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Personal assistance for disabled people and the understanding of human being

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Abstract

This paper explores personal assistance – a practice considered crucial for supporting the independence and social inclusion of disabled people. The starting point of the analysis is the presumption that the significance of personal assistance goes well beyond welfare, touching upon existential-ontological issues. In order to uncover these issues, a phenomenological approach is used. The aim is to highlight the understanding of human being which is mediated by an internationally prominent model of personal assistance, to wit, the one promoted by the European Independent Living advocates, as described by Adolf Ratzka (2004a). It is argued that despite its liberal-individualist assertions the scheme described by Ratzka presupposes a distributed, relational understanding of human being. A case study of recent disability-related activism in Bulgaria is developed in order to further substantiate this claim. In conceptual terms, then, the paper adds a fresh perspective to the debates on individualist vs. collectivist approaches to disability equality. This perspective is informed by the phenomenological insights of Martin Heidegger (1962) and Maurice Merleau-Ponty (2002). In policy terms the paper argues for the necessity of promoting and supporting disabled people's self-organising, most importantly peer support and advocacy activities.

Keywords: disability, independent living, phenomenology

Introduction

In October 2010 disabled people from all over Bulgaria took part in an event called *Freedom March*. Held in the capital for a second consecutive year, the public action was conducted under the slogan ‘Adopt a law for personal assistance and grant us freedom!’ The event was inspired by another rally – the *Freedom Drive*, organised bi-annually in Strasbourg by the European Network on Independent Living (www.enil.eu), an international disabled people’s organisation advocating for Independent Living. Among the main messages addressed to politicians and the general public in both the Bulgarian *Freedom March* and the European *Freedom Drive* is the claim that personal assistance is an essential condition for disabled people’s freedom. Hence, it should be recognised as a human right and be provided for by the state.

These advocacy efforts of disabled Europeans demand for relocation of welfare resources – most notably from institutionalised and/or professionalised care towards direct payments (also known as ‘cash benefits’ or ‘individual/personal budgets’). But their stake is more than economic redistribution. Descending from the disability activism of the 1970s, they demand cultural *recognition* as insistently as they demand economic redistribution – a feature which characterises new social movements in general (Fraser, 1997; Oliver and Zarb, 1989). Consequently, economic or welfare rationality alone cannot provide adequate means for understanding disabled people’s claims for freedom and independence – neither can it ground them. To this end, questions of *having* need to be put in context by attending to questions of *being*. Such reasoning is consistent with recent developments in disability studies which endeavour to explore the existential-ontological dimensions of disability-

related issues (e.g., Campbell, 2009; Hughes, 2007; Schillmeier, 2010). What is called for is an enquiry into the very *understanding of human being* which underpins disability advocates' demands for redistribution.

The results of such enquiry are not immediately given or obvious. Understandings of our being permeate our actions, but remain transparent and invisible, like the air we breathe. As phenomenologists like Heidegger (1962: 36) have pointed out long ago, 'that which is closest' to us in our everyday living – to wit, our own *being* – is also 'that which is farthest' in terms of its *meaning*. Crudely put, I always and necessarily experience myself as in being (*that* I am), but I usually do not explicitly consider the meaning of this experience (as *what kind of entity* I am). In experiencing myself, do I understand myself as a self-determining, self-governing, autonomous entity – as a 'thinking thing', a subject? Or do I understand myself as a delimited, fixed, physical entity – as a body, an object, an 'extended thing'? Or do I understand myself as a useful entity, a 'human resource'? Or do I understand myself as part of a greater whole, as always already extending towards things and others in my surroundings – in phenomenological vocabulary, as 'being-in-the-world' (Heidegger, 1962; Merleau-Ponty, 2002)?

Importantly, the understanding of our being is not stored in unconscious belief systems, but is embodied in what we do (Dreyfus, 1991: 16-23). In other words, 'our social practices embody an ontology' (Dreyfus, 1991: 16). Hence, phenomenology insists that we should look at the activities in which we are immediately involved in order to highlight the more general existential-ontological patterns of our living. In the words of Merleau-Ponty (2002: vii), phenomenology 'puts essences back into existence, and does not expect to arrive at an

understanding of man and the world from any starting point other than that of their ‘facticity’” (see also Wrathall, 2006). It is this basic phenomenological insight which provides conceptual guidance for the present study.

As has already been pointed out, both the European *Freedom Drive* and the Bulgarian *Freedom March* demanded personal assistance. For the advocates of disabled people’s rights this disability-related practice is absolutely pivotal (Ratzka, 2004a: 2; see also Spandler, 2004: 192-193). Its crucial importance has also been recognised in international documents like the UN *Standard Rules on the Equalization of Opportunities for Persons with Disabilities* (Rule 4) and the UN *Convention on the Rights of Persons with Disabilities* (Article 19). The significance of personal assistance for disability equality can be compared to the significance of rational debate for deliberative democracy – i.e., personal assistance is a major condition for the possibility of disability equality just like rational debate is a major condition for the possibility of deliberative democracy. Consequently, the best way to explore the understanding of human being underpinning not only the recent advocacy efforts mentioned above but also a great deal of disability activism over the past 40 years (Barnes, 2007: 348-350) is to study those statements and demands of disability advocates which concern the organisation and provision of personal assistance.

Hence the question which I would like to address in this text: What understanding of human being is mediated by the practice of personal assistance as promoted by the Independent Living advocates? My attempt to articulate an answer will be complemented by an exploration of those existential-ontological meanings which are being challenged by the advocates. My point of departure is the observation that a significant degree of consensus

exists among Independent Living advocates on the particularities of the ‘ideal’ mechanism for the provision of personal assistance. Consequently, advocacy efforts such as the Bulgarian *Freedom March* and the European *Freedom Drive* are as much for principles as for practices – or rather, these instances of advocacy clearly exemplify how principles are always and necessarily embodied in practices. Actually, more often than not the fight is *not* over ideas but over the particularities of the practices which translate ideas into realities of everyday living. Looking at personal assistance schemes and their effects on disabled people’s lives and self-understanding, one cannot help the persistent feeling that both god and the devil are in the details.

It is hoped that this paper will make a phenomenologically informed contribution to the long-standing debates within disability studies over the ideological underpinnings of Independent Living, direct payments, and personal assistance in particular (e.g., Barnes, 2004; Pearson, 2000; Spandler, 2004; Williams, 1983). These debates have focused on the tension between individualist and collectivist approaches to disability equality. I will argue that even in their plainly individualist suggestions, Independent Living advocates presuppose a distributed, relational understanding of human being. The policy corollary will be that it is imperative to promote and support disabled people’s self-organising if individually designed Independent Living solutions are to succeed.

The ECEPA project

As already noted, many Independent Living advocates, including the participants in the Bulgarian *Freedom March* and the European *Freedom Drive*, share an understanding of

the best way to organise personal assistance. In 2004 such consensus was authoritatively articulated in a document entitled ‘Model national personal assistance policy’ (Ratzka, 2004a). It was an outcome of an international project for exploring and promoting best practices in personal assistance for disabled people called *The European Center for Excellence in Personal Assistance* (ECEPA). The project’s website describes ECEPA as:

an initiative of major Centers for Independent Living in Europe and their respective networks consisting of grassroot groups of disabled people, most of whom are users of personal assistance, with a long experience of helping each other move out or keep out of residential institutions. (www.ecepa.org/mission/index.htm)

The project included disabled people’s organisations from nine European countries: Germany, Sweden, Finland, Norway, Ireland, Austria, Italy, Greece, and Switzerland (Ratzka, 2004a: 1). Unlike traditional social policy, whose development is dominated by experts, the ECEPA project was designed as a ‘bottom-up’ initiative, an instance of policy-making in which practice and personal experience preceded theory and impersonal generalisations. It was coordinated by Adolf Ratzka – an internationally renowned Independent Living activist and author, one of the pioneers of the Independent Living movement in Europe.

The movement itself was initiated by disabled Americans, who set up the first personal assistance schemes as early as in the 1970s by establishing a network of Centres for Independent Living in the United States (Barnes, 2007; DeJong, 1979). In the 1980s Ratzka ‘imported’ these ideas and practices into Sweden and founded the Stockholm Cooperative for Independent Living (www.stil.se) – the first European user-led cooperative for personal

assistance (Ratzka, 2004b). It provided disabled people with the opportunity to live independently outside residential institutions by hiring their own personal assistants. Subsequently, the practices developed and tested in the Stockholm Cooperative served as the model for the Swedish Personal Assistance Act of 1994. This legislation has been regarded by disability activists and analysts as a ‘gold standard’ in the area of personal assistance (Anderberg, 2009: 2). It had a significant impact on the ECEPA model as well.

In the next sections I will explore the description of the model, compiled and edited by Ratzka himself (2004a). It meticulously outlines each and every detail of ‘ideally’ organised personal assistance, as envisioned by European Independent Living advocates – themselves users of personal assistance. I will argue that the ECEPA model exemplifies a description of social policy practice that is sensitive not only to the material and psycho-physiological exigencies of being disabled in present-day Western society (which it undeniably addresses), but also to the ways in which the practice *defines people who engage with it in their very being*. Hence, it is a phenomenologically promising description, one which is attentive to the existential-ontological implications of the support mechanism it promotes.

From autonomy to inter-dependence

According to the ECEPA model, an ideal policy for personal assistance will make it possible for disabled people ‘to live in the community, as equal and fully participating citizens’ (Ratzka, 2004a: 1). The mechanism is contrasted with more traditional, top-down, professionalised social-policy solutions (or lack thereof) that make people totally

dependent on charity, on their families of origin, or exclude them in residential institutions. Accordingly, the model regards the full human being in terms of ‘self-determination’ and ‘full citizenship’ (Ratzka, 2004a: 2). It grounds this status in the possibility of exercising choice and control. Yet such choice and control are not primarily concerned with the ordinary everyday activities that people perform, say, when deciding what subject to study at university or which channel to watch on TV. Rather, the choice and control promoted by the ECEPA model *in the first place* are of a higher order – they are concerned with the support one needs in order to exercise choice and to have control in the ordinary sense. Thus the properly organised personal assistance allows disabled people ‘to choose their preferred degree of personal control over service delivery according to their needs, capabilities, current life circumstances, preferences and aspirations’ (Ratzka, 2004a: 3).

In more concrete terms, the service user is empowered to choose and control ‘who is to work [as his/her assistant], with which tasks, at which times, where and how’ (Ratzka, 2004a: 3). This is provided for through a complicated system of interrelated measures which specifies how disabled person’s needs assessment, direct payments and accountability should be organised. The system comprises many subtle details, for example: insistence on decoupling eligibility criteria from medical diagnosis and income; requirement to cover personal assistance needs in all areas of living, including assistance inside and outside home, at school, at work, during leisure time, etc.; requirement to express assistance needs in assistance hours rather than in terms of specific services needed; requirement to have one central funding source on the national level instead of many dispersed local funding bodies; requirement to cover all assistance-associated costs and not only the assistant(s)’s wage(s); etc. (Ratzka, 2004a: 4-7). Each and every one of

these elements is crucial for the functioning of the scheme as a whole, notwithstanding that the emphasis is often put on the principle that disabled people should receive cash benefits (direct payments) instead of services in kind (Ratzka, 2004a: 5). Yet this principle should not be treated in isolation from the other measures suggested by the model, neither should the scheme be reduced to a financial transaction between a ‘funding body’ and a ‘service user’.

In order to understand the ECEPA model and by extension personal assistance as promoted by Independent Living advocates, one needs a different ground. As suggested at the beginning of this paper, such ground might be secured by phenomenology, providing its attention to the meaning of being as mediated by practices. Thus from a phenomenological perspective the whole system of interrelated measures, summarised in the preceding paragraph, mediates a specific understanding of what it means to be a (fully) human being. Such understanding hangs on the opportunity to have choice and exercise control over the assistance one receives in order to go about one’s everyday living (see also Morris, 2004: 427-429; Stainton and Boyce, 2004: 449). Accordingly, *to be fully human does not mean to cope without assistance*. This implies a shift of meaning with significant social and political consequences because personal assistance radically changes our general understanding of *independence*. Instead of *autonomy*, it now means a particular type of *inter-dependence*. This shift is neatly captured and emphasised in the definition of ‘independent living’, provided on the website of the European Network on Independent Living, where we read:

Independent living does not mean that disabled people want to do everything themselves or live in isolation because we know that *all people whether they are*

disabled or non-disabled are interdependent.

(http://www.enil.eu/enil/index.php?option=com_content&task=view&id=3&Itemid=84, emphasis added)

Putting the shift in context

The shift of the meaning of ‘independence’, urged by the Independent Living advocates, shatters deep existential-ontological and socio-political intuitions inherited from the European Enlightenment. An example will make the point clear. The Kantian distinction between the private and the public spheres hangs on the principle that ‘the individuals comprising the public are endowed with a rational will which is independent of all empirically existing institutions and experience’ (Schechter, 2010: 190). In his widely discussed article ‘An answer to the question: What is Enlightenment?’ Kant (1991a: 54) defines Enlightenment as the moment in which humans become ‘mature’, that is, autonomous in their use of reason. Importantly in the context of the present discussion, Kant (1991a: 54) uses the metaphor of ‘walking alone’ to illustrate his idea of autonomy (on the cultural politics of ‘walking’ metaphors see Oliver, 1993). Kant (1991a: 54) stipulates that ‘maturity’ would be considered dangerous and difficult by the ‘entire fair sex’ which is bound to private use of reason, inherently restricted by obligation, convention, prejudice, etc. In another of his important political writings Kant (1991b: 77) also declares that in order to be a full citizen, that is, to have the right to co-legislate, the person ‘must be his *own master (sui iuris)*, and must have some *property* (which can include any skill, trade, fine art or science) to support himself’. At that ‘[t]he domestic servant, the shop assistant, the labourer, or even the barber, are merely labourers (*operarii*),

not *artists* (*artifices*, in the wider sense) or members of the state, and are thus unqualified to be citizens' (Kant, 1991b: 77).

This Kantian logic suggests that humanity is at its best when it is abstracted from all particularities of historically contingent institutions, including formal and/or informal support systems. The corollary is that:

Kant openly excludes women, children and salaried workers from the public sphere because of their supposed lack of autonomy. In his estimation they are emotionally and economically dependent, which means that if allowed to participate in public affairs, they are likely to embrace a politics of irrational need rather than a juridical politics of freedom and rational cognition. If this happens, law is deprived of its epistemological dimension at the same time that the transcendence of natural and mechanical necessity is forfeited. (Schechter, 2010: 191; see also Brenner, 2006)

Such reasoning would similarly exclude disabled people from the public sphere for they are by definition implicated in different formal and informal systems of support. Actually, such exclusion has been exposed and criticised by many disability scholars and advocates as a historical fact (e.g., Barton, 1993; Beresford and Campbell, 1993; Meekosha and Dowse, 1997). The ECEPA model challenges the very logic on which the exclusion is based, together with its attendant dis-embodied and dis-embedded Kantian view the subject (Han Pile, 2005: 89-90). Through a carefully devised scheme for a user-led and user-centred support, it suggests in a very material and practical way that independence is not a matter of autonomy but of a *particular type of inter-dependence*. On this reading one *can* be dependent and fully human, that is, 'endowed with rational will' and entitled to

participate in the public sphere. What is more, one is always already inter-dependent and the attainment of ‘fully human’ status is contingent upon modifying or structuring this foundational inter-dependence in a certain way. This is the important phenomenological lesson to be drawn from the ECEPA model.

It is enough to think about the myriad ways in which present-day people are implicated in different support systems ranging from transportation through telecommunication to food and health services in order to see the plausibility of such claim. Let me recourse again to phenomenological vocabulary and grammar borrowed from Heidegger’s (1962: 102-107) analysis of equipmental failure in order to exemplify the point. Proximally and for the most part the infrastructural networks in which we are implicated remain transparent and therefore hidden for us. They become conspicuous, obtrusive or obstinate in situations of breakdown, for example when the public transport workers go on strike. In such moments we feel vulnerable, fragile, exposed. We become anxious. Support network cease to be user-centred and our foundational inter-dependence announces itself anew.

Self-driven customers?

Notwithstanding this focus on inter-dependence though, it might be argued that the ECEPA model still presupposes detached, individualised, autonomous decision-making. It seems that the liberal individual – the heir of the autonomous Kantian subject of the Enlightenment (Sandel, 1998; Schechter, 2007) – is more or less tacitly posed as a condition for any non-oppressive inter-dependence. The reason is the stipulation that *only a sovereign subject can choose and be in control of his/her assistance* – and, by implication, of his/her

existence. On this reading the ECEPA model, indeed, shifts the traditional meaning of independence from autonomy to inter-dependence, but only by grounding this inter-dependence in an even more robust form of autonomy – that of the sovereign subject. Hence personal assistance might be said to deconstruct the view of the *body* as a detached entity by exposing and normalising the ways in which its materiality is distributed within networks of assistive practices (I borrow this notion of ‘distribution’ from the work of actor-network theorists within disability studies like Moser, 2006: 383). Yet critics would retort that the price for such deconstruction is further consolidation of the autonomy of the *mind*. Philosophically speaking, such move reasserts Cartesian mind-body dualism (Crossley, 2001: 8-21) and with it the Kantian reduction of the human to a rational, sovereign, universally legislating subject (the connection between Descartes and Kant has been critically highlighted by phenomenologists – see Heidegger, 1962: 248 and Merleau-Ponty, 2002: x).

Is this the case? Does the ECEPA model really suggest that *only a sovereign subject can choose and be in control*? In order to answer this question, one needs to pay attention to the precise ways in which the model uses the notions of ‘choice’ and ‘control’. And indeed, it seems that Ratzka’s description deploys these ideas in exclusively liberal-individualist vein. The ECEPA model envisions disabled people as ‘assistance users with purchasing power which, in turn, creates a market for assistance services’ (Ratzka, 2004a, 2) and states that, ‘[s]imply put, “personal assistance” means the user is customer or boss’ (Ratzka, 2004a: 3). These ideas are emphatically re-emphasised in a footnote proclaiming that ‘[c]ash payments create a market with competing providers and *turn users into customers who have a choice and can demand quality*’ (Ratzka, 2004a: 5, n. 12, emphasis added).

Obviously, such claims render disabled people in terms of self-driven consumers who sovereignly wield the power to buy. They are rooted in the (neo)liberal belief in unleashing free-market forces which are allegedly going to eliminate monopolies and improve the diversity and quality of services provided (on the significance of market discourse and consumerism for direct payments schemes see Pearson, 2000; Spandler, 2004). Disability scholars, especially those working in the area of intellectual impairments, have been strongly critical of this paradigm (Dowse, 2009).

Yet I will argue that there are aspects of the ECEPA model which complicate and even undermine this liberal-individualist logic with its attendant reduction of the human being to a self-sufficient, detached, rationally calculating subject. On a practical level, that is, in terms of organisation of personal assistance, the model in fact presupposes a *decentred, distributed understanding of choice and control*. The reason is that, in order to be ‘sovereign’ and ‘independent’, the choice and control exercised by disabled people over their assistance need to be supported *themselves* by a certain infrastructure. In the next section I will draw its outline, highlighting those elements of the ECEPA model which most directly concern the infrastructure supporting the user’s decision-making.

Choice and control revisited

Let me begin with the more conspicuous ones related to *children and people with mental impairments*. A stringent liberal-individualist logic would suggest that it is not possible for such individuals to be ‘customers’ or ‘bosses’ in the strict sense because of their lack of capacity for sovereign decision-making. Yet the ECEPA model explicitly refuses to

exclude from its purview those who are deemed incapable to choose and control their assistance *on their own*. Instead, it stipulates that children and cognitively or psychosocially impaired users ‘might need support from third persons with [the] functions [of customers or bosses]’ (Ratzka, 2004a: 3). Hence the model admits that others might be involved in one’s decision-making without that compromising the basic tenets of the scheme – that is, the notions of choice and control. What is more, it not only suggests that choice and control can be distributed through delegation to third persons, but also that such distribution should be financially acknowledged and supported by the scheme:

Citizens who, despite appropriate information, counseling and other support, are unable to select and evaluate services or to employ their assistants themselves can also benefit from the policy provided that they receive the support from third persons such as a legal representative, family member or other person close to them. The costs of such support need to be covered by the policy, if necessary, by higher payments for the average assistance hour. (Ratzka, 2004a: 3, n. 4)

A crucial question remains, though: Does the ECEPA model apply its distributed understanding of decision-making to other categories of users besides children and intellectually or psychosocially impaired people? In other words, does it admit that the assistance-related choices of (allegedly) sovereign decision-makers are also in some ways socially and materially distributed? An answer has already been prompted by the above quote which presupposes the availability of ‘information, counselling and other support’ prior to more conspicuous forms of distribution like delegation of decision-making power to third persons. For one, the model suggests that the activities of choice and control require the mastering of specific *skills*. It envisions that by using the personal assistance scheme

people can ‘try assistance solutions with varying degrees of user responsibility and, step by step, at their own pace, ... *develop the skills required to take on more control over their services*’ (Ratzka, 2004a: 3, n. 3, emphasis added). But skills are acquired through socialisation, which highlights the need to contextualise the roles of ‘customer’ or ‘boss’ even in cases where the conventional ‘sovereignty’ of decision-making is not at stake.

This last point is also suggested by those elements of the ECEPA model which concern *peer support*. Generally speaking, self-help has long been recognised as a major pillar of the disability movement (Oliver and Zarb, 1989: 230). In his recent analysis of ‘direct payment’ schemes in the UK Colin Barnes (2007: 352) states it clearly:

From the outset it was recognized by the disabled people’s organizations that for disabled people to use direct payments effectively they need appropriate support. This may include help with advertising, recruitment, wages, management skills, employment law, etc. Indeed, many disabled people have never been employed themselves and so the idea of employing personal assistants is often especially daunting. Such services were pioneered by CIL-type organizations during the 1980s and 1990s.

The ECEPA model also envisions peer support as pivotal for the functioning of any personal assistance scheme. Thus when the disabled person’s assistance needs are being assessed, an opportunity is provided for him/her to be supported by an individual of his/her choice (Ratzka, 2004a: 4). More generally, ‘[i]n all contacts with the funding agency’s staff regarding needs assessment, appeals or other administrative issues assistance users can utilize the counsel and support of third persons of their choice, in particular, other personal

assistance users' (Ratzka, 2004a: 5). Peer support is also considered essential in information, training, and advocacy activities related to the use of personal assistance (Ratzka, 2004a: 4, n. 8 and n. 18). Finally, among the costs which should be covered by the scheme are those of 'training and support of assistance users ..., if deemed necessary by the user' (Ratzka, 2004a: 7).

My conclusion is that the ECEPA model, at least implicitly, promotes a distributed understanding of human being, one which is commensurable with the phenomenological notion of being-in-the-world (Heidegger, 1962; Merleau-Ponty, 2002). From such a perspective to be fully human does not mean to be autonomous in any material and/or ideal sense. Neither the objectively delimited 'healthy' body nor the subjectively delimited 'sovereign' mind can serve as ultimate existential-ontological reference points for proposing social policy solutions to disability-related problems. One needs a much more contextualised or relational understanding of human being in order to combine economic redistribution with cultural recognition in the quest for social justice (Fraser, 1997). Without being determinable in any case, free choice and subject-centred control are nevertheless *mediated* by choice-facilitating practices in which humans engage in their being-in-the-world. This might seem puzzling, but only if we stick to an understanding of 'independence' as 'autonomy' in the liberal-individualist way. On the other hand, if we understand 'independence' as a *particular type of inter-dependence* (as suggested above), the empuzzlement dissolves. I will revisit this point in my concluding remarks.

Collective action for legislative change

Personal assistance is related to inter-dependence in yet another sense. This is the sense of collective public action, which characterises social movements in general, no matter whether ‘old’ or ‘new’ (Stammers, 1999: 984-985). As I mentioned earlier, personal assistance of the type described by Ratzka emerged in the 1970s out of the self-organising of disabled people in their quest for independence (DeJong et al., 1992). The Independent Living movement, first in the United States and then in Europe, has made it possible for disabled people to claim control over their own lives not only through an economic redistribution of welfare resources but also through a ‘pedagogy of the oppressed’ (Freire, 2006) – i.e., disabled people taught each other how to manage their own assistance, gaining insights into new possibilities of being. Developing a network of user-led Centres for Independent Living, the movement has provided ongoing support in the form of peer education and counselling for disabled people who wanted to live differently. It has also served as a watchdog of personal assistance policies, constantly monitoring and assessing their complicity with models like the ECEPA one, developed by assistance users themselves. Thus over the years the personal assistance scheme has retained strong connections with certain ways of being and acting together, as a community. Let me recount a recent example of such collective action. What follows is an ‘insider’s account’ in which I draw both on a review of existing documents and on my own knowledge and experience gained over nearly ten years of engagement with the Independent Living movement in Bulgaria.

The Bulgarian *Freedom March* of 2010, mentioned in the beginning of this paper, demanded the adoption of a law for personal assistance. The public action, organised in Sofia for a second consecutive year, was in support of a new bill developed by the

advocates themselves. So far, a number of similar attempts for legislative innovation had repeatedly encountered strong resistance from the social policy establishment (Dakova, 2004; for recent developments see www.lichna-pomosht.org). Notably, such innovations were significantly hindered by the big ‘nationally representative’ organisations of and for disabled people that have for a long time been co-opted by the authorities (Mladenov, 2009). In addition, the government Agency for social assistance (www.asp.government.bg) had recently announced its own programme for ‘individual budgets’ – heir of a number of similar governmental ‘care’ programmes for disabled people, implemented since 2002. Their availability has always been a strong argument against any claims for change: ‘We already provide what you demand!’ Yet what the government institutions have provided has consistently been very different both in its details and in its principles from the personal assistance scheme proposed by the *Freedom March* participants (for a critical overview see CIL, 2009a). In sum, the failed attempts in the domain of ‘rational deliberation’ reemphasised the need for direct action and on the 21 October, 2010, disabled Bulgarians took to the streets of Sofia.

The march was organised by the Centre for Independent Living – Sofia (CIL) – a Bulgarian non-governmental organisation of disabled people that has been advocating for independent living since 1995. According to CIL’s website (www.cil.bg) the public action was supported by disabled people from all over the country, the number of participants exceeding one hundred. Another Bulgarian website for disability activism (www.lichna-pomosht.org) published photographs from the march, as well as videos from its media coverage. Unsurprisingly, both these internet sources depict and interpret the event in

markedly activist-collectivist terms. The reports stress the quantity of people gathered and the strength of their collective will for change:

The memorable date was 21 October, 2010 – memorable because of the significantly greater number of people who were not afraid of the mild but annoying drizzle and bravely stated their firm will to seek responsibility from the Bulgarian MPs for the lack of personal assistance, regulated by a law. Over 100 disabled people from Burgas, Kazanlak, Novi pazar, Simeonovgrad, Sofia, Stara Zagora and probably from many other places came in front of the Council of Ministers...

(www.cil.bg/Новини/126.html)

The number of people is ‘significantly greater’, they are ‘over 100’; they come from numerous towns and cities, some of them enumerated, but ‘many other’ implied; they are ‘not afraid’ and ‘bravely’ state their ‘firm will’ – it is hard to overlook the vocabulary and grammar of collective emancipatory struggle. A distributed, communal mode of being is summoned as a ground on which to build the claims for individual liberation. The advocates also emphasise that the personal assistance bill they propose is a joint product, rooted in the common experience of everyday disability-related hardships: ‘We wrote it [the bill], devoting time and care – we, the people who need it’ (www.cil.bg/Новини/117.html). These references to collective subjectivity are vital ingredients of the demand for progressive legislative change voiced by the disabled Bulgarians, especially in the context of the overmedicalised and highly paternalistic system of Bulgarian disability-related social policy (International Disability Network, 2007: 63-96). Such acknowledgement does not mean a blind endorsement of identity politics because the collective subject summoned by the Bulgarian *Freedom March* is not homogeneous.

Or rather, the emphasis is more on collectivity than on subjectivity. In any case, it seems obvious that the concerted action of many is needed in order to bring about the legislative conditions for the independent living of each and every one in particular.

Collective action after legislative change

What is less obvious is that such collective mode of being does not automatically become obsolete when legislative changes supporting individual emancipation take place. Quite the contrary! Looking at the disability-related activism in Britain just before the passing of the Disability Discrimination Act 1995, Barnes and Oliver (1995) warn that the adoption of anti-discrimination legislation in the disability area should not be regarded as an end in itself but as a means. In itself, it is not enough. Rather, ‘civil rights will only be achieved through the adequate funding of the nationwide network of organizations controlled and run by disabled people themselves’ (Barnes and Oliver, 1995: 115). Eleven years later the two authors reiterate this concern about the ground-laying role of the disability movement, this time sounding a more pessimistic note:

since the turn of the millennium we have witnessed the growing professionalisation of disability rights and the wilful decimation of organisations controlled and run by disabled people at the local and national level by successive government policies despite rhetoric to the contrary. As a result we no longer have a strong and powerful disabled people’s movement and the struggle to improve disabled people’s life chances has taken a step backwards. (Oliver and Barnes, 2006: n.p.)

The corollary is that, without collective action and thought, the success of civil rights legislation is questionable, to say the least. The same applies to any actual or proposed legislation for personal assistance for Independent Living. The impending permanent closure of the Independent Living Fund in the United Kingdom will put this claim to a painful practical test, but I would like to substantiate it here with a recent example from Bulgaria. It is related to the personal assistance scheme funded and managed by the Sofia Municipality. The ordinance for its provision was adopted in 2007, after years of advocacy and lobbying on behalf of the Independent Living activists in the capital. Finally, on 26 July, 2007, the Municipal Council passed the local bill. The legislation had been developed by the disability advocates themselves and was strongly influenced by the ECEPA model analysed above. Thus in 2007 disabled inhabitants of the Bulgarian capital started benefiting from personal assistance which approximated the European ‘gold standard’ in the area. Yet before long – in January 2008 – the ordinance was clandestinely amended; and shortly after, in November 2008, it was amended again. The changes prompted the Centre for Independent Living – Sofia to evaluate the provision of the service by the municipal authorities. In 2009 the organisation submitted to the Municipal Council in Sofia an evaluation report, written in partnership with the Department of Sociology at Sofia University (CIL, 2009b). The report strongly criticised the current enforcement of the scheme by the municipal authorities.

The document was hailed by some of the municipal councillors but largely disregarded by the municipal administration. Eventually, in 2010, 45 disabled people, most of them personal assistance users, signed a protest letter addressed to the Ombudsman of the Republic of Bulgaria. In this document the claimants state that during the initial phase of

its enforcement the municipal ordinance on personal assistance ‘helped a lot of disabled people to start living a more dignified and independent life’. ‘Unfortunately’, they continue, ‘during the further implementation of the ordinance a lot of problems emerged and Sofia Municipality, instead of improving the lives of the disabled people, embarked on their blatant harassment’ (www.cil.bg/userfiles/media/do_ombudsmana.doc).

Thus a hard-won legislative battle evolved into a set of skewed practices, in some cases turning the initial ideas on their heads. The evaluation report and the protest letter cited above did not produce any (immediate) effects. Nevertheless, these collective and public efforts at social policy critique highlighted issues which would otherwise remain deeply hidden from the general public. Both the report and the letter bristle with details. They explain how seemingly small changes in the regulation and provision of personal assistance have resulted in huge deviations from the Independent Living framework, originally underpinning the legislation. As I have already shown in my discussion of the ECEPA model, the details of the personal assistance policy shelter gods and devils alike. It seems that only a conceptually and organisationally strong community can keep gods happy and devils at bay. The backbone of personal assistance is disabled people’s self-organising – both before as well as *after* the appropriate legislation takes place. Colin Barnes (2007: 353) has stated recently that in order to have a working ‘direct payments’ scheme in the UK, what is needed is ‘to develop and support a nationwide network of locally based user-controlled organizations providing services for local direct payment users’. Similar considerations have been put forward by Morris (2004: 438-439), Stainton and Boyce (2004: 444-445) and others. Some disability scholars have also argued for the development of politically ‘stronger and more unified action for greater resources and input into resource

distribution’ (Spandler, 2004: 204) on behalf of the recipients of direct payments. The Bulgarian case described here corroborates these suggestions.

Concluding remarks

For the past 40 years, Independent Living advocates have been fighting for certain practices which are meant to enable disabled people’s choice and control over important aspects of their lives. Among these practices personal assistance stands out as pivotal. Although financially based on the mechanism of ‘direct payments’ (or ‘cash benefits’ / ‘individual budgets’), it should not be reduced to financial transactions taking place among institutions and individuals – neither should choice and control be reduced to self-driven actions of autonomous decision-makers, with their self-explanatory consumer preferences. As described in ‘ideal’ models like the ECEPA one, personal assistance comprises a patterned network of interrelated activities, involving needs assessment procedures, intricate funding and accountability arrangements, appeal options, and, importantly, peer training, support, and counselling. From a phenomenological point of view such network mediates a particular understanding of human being. I have argued that such understanding is better articulated through notions like inter-dependence and distribution (of embodied action and/or decision-making) than through the liberal framework of individual autonomy.

Nevertheless, tension between autonomy and inter-dependence characterises the Independent Living movement *from the inside*. The clash within the movement between the liberal-individualist and the structural-collectivist frameworks has long ago been identified and commented on (Williams, 1983; for a recent discussion see Gibbs, 2005). It

would be all too easy (or naïve) to dismiss the ECEPA model's recourse to notions like 'customer' or 'boss' as mere rhetorical devices or as instances of purely strategic appropriation of liberal-individualist language and grammar. Still they *do have* a strategic function – to wit, to challenge traditional forms of 'care' which significantly restrict disabled people's possibilities, understood not only in the material, but also in the existential-ontological sense, as possibilities of being. Merleau-Ponty (2002: 523) points out that 'in any case freedom modifies [history] only by taking up the meaning which history *was offering* at the moment in question, and by a kind of unobtrusive assimilation'. Similarly, the ECEPA model takes up and assimilates the meaning offered by the historically dominant (in the West) liberal individualism in order to fight the traditional reduction of disabled people to passive objects of care interventions. Such strategy is characteristic of the Independent Living movement in general; its advocacy for consumer sovereignty and self-reliance has made it prone to critiques of favouring 'only a relatively small section of the disabled population: notably, young intellectually able, middle class white males' (Barnes, 2004: 8). A careful exploration of 'ideal' schemes for personal assistance for Independent Living like the ECEPA one, though, shows that they devise a system of measures which effectively contextualise and distribute the sovereignty and autonomy of individual action and decision-making. Both strategies – the liberal-individualist and the structural-collectivist one – need to be taken into account. The crucial point is to understand the former in the context of the latter and not *vice versa*.

Translated into policy terms, this means that it is imperative to promote and support disabled people's self-organising – with regard to peer support as well as with regard to collective watchdog and advocacy activities. In the second part of the paper I have tried to

develop this suggestion by showing that the very *fight* for the practice of personal assistance, with its characteristic forms, visions, language, etc., this fight *itself* mediates an understanding of humans as interdependent, distributed, contextually embedded beings. This hints at the intrinsic relationship between the two major forms of mediation explored in the text – the one related to the *practice of personal assistance* and the one related to the *practice of its collective vindication* in the public sphere. From such perspective there can be no personal assistance for Independent Living without the collective action of self-organised personal assistance users. The reasons for this are complex and their exploration goes well beyond the scope of the present paper. I can only sketch here their general and preliminary outline.

Freedom, understood in terms of ‘independence’, is possible only on the basis of a shared world – a foundational network of inter-dependencies. This insight has been captured by 20th century phenomenologists like Heidegger (1962: 78), who has denoted the most basic state of human being as ‘being-in-the-world’. Later, Merleau-Ponty (2002: 530) has explained the logic of ‘being-in-the-world’ thus: ‘Nothing determines me from outside, not because nothing acts upon me, but, on the contrary, because I am from the start outside myself and open to the world’. It is the shared world in which people are always already implicated which provides them with the means to *individualise* themselves. Yet another condition for ‘independence’ is the possibility to reflexively engage with the world of one’s being – for ‘if one is not free to adjust the limits of freedom, citizenship is a trap and one can be considered to be free in prison’ (Schechter, 2010: 227). From this perspective an individualised human being needs to have access to the infrastructures mediating his/her individualisation. Such access should allow continuous readjustment of these

infrastructures themselves, which can never be fixed once and for all but require constant problematisation and re-enactment. A condition for this is collective action – only collective action can keep the infrastructures mediating one's individualisation open for access, problematisation and readjustment.

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